



# 2016 CLL Patient Café: Coping With the Emotional Roller Coaster

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**Elaine**

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Host and CLL Patient

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**Carol Preston:**

And we want to talk about lifestyle changes and how they've helped. But you have been practicing all of your wonderful things that you practice for 40 years. So from diagnosis, any particular tweaks in the last five years that you've made that just course correction once you got the diagnosis?

**Elaine:**

Yeah, actually. I was fortunate. It took me 70 years to find a spiritual community that actually spoke my language and practiced the way I would want to.

And I am just so grateful to have found them just in time for this diagnosis. And one of the first things that I did was to try to, even though I already live a pretty minimalist life, was to pare it down even more. And I am much more careful about who I interact with that I want the people around me to be positive, loving, caring souls and without negative energy. And the other really big thing, for me, I'm an independent cuss, always have been. I've divorced my husband after 36 years of marriage 20 years later than I wanted to and live alone and love it. And I never ask people to do anything for me. And all of a sudden, I enter a clinical trial where I was getting diphenhydramine (Benadryl).

And I could not do my own driving back and forth. And for the first time, I had to allow vulnerability into my life, which was a big thing for me. And I developed a website on the Lots of Helping Hands Community website. And all through my trial, blogged about my experience. It's mostly about faith, hope and trust, and gratitude. And there's an appointment calendar where you can put dates when you need help. And I would put my driving dates, which were always at rush hour, Boston traffic rush hour, early morning, and Boston rush hour late afternoon.

And within three hours, every time I would put up those appointments, they were filled.

Those spots were filled. And people came from all over to come and pick me up at 6:00 in the morning and bring me home at 7:00 at night.

**Carol Preston:**

So by connecting with people who you felt would ask for an aura of positivity and love, there's just no issue and no stress about getting the transportation that you need. I mean, it's more than just getting the transportation. But it's the people that you have surrounded yourself with.

**Elaine:**

Exactly.

**Carol Preston:**

You mentioned a really important word, which I'd like to explore with Jay, let me start with you. This word vulnerability, and I can really kind of empathize, because I feel I'm very independent as well. And suddenly, with a diagnosis whether it's CLL or whatever the cancer, suddenly, there's a vulnerability.

And there's a loss of control, I think, which is very, very frightening. And more than that, can I get any control back? And I'm just wondering, Jay, as you talk about the connection between mind and body, if you experienced anything similar. And then we'll speak with Derrick and Lisa again.

**Jay:**

Well, I think so. I mean, I sort of developed this mantra, which is not today and probably not tomorrow. And to me, it means that you are vulnerable. And I have no idea how my health will evolve over the next time period. Things could go very well for 10 years. And they could start to go sideways at any time. So I live, we all live, with that uncertainty.

And there's absolutely no way to control that. I mean, we can do our best in terms of maintaining physical health through diet or whatever other means. But still, at some point, it's likely, in my case, at my age, that the condition will worsen. But that's not today, and it's probably not tomorrow. And that's what I have in front of me. I'm not a long-range planner in the first place. I rarely think more than a few months ahead. And I don't make vacation plans for two years from now.

I never have. So I think that the experience has made me really consolidate my day-to-day life and look at what I can do today and what I can enjoy today and detach from other smaller concerns.

**Carol Preston:**

How about the importance of your family and your kids who, gosh, at this point, how old are your children now?

**Jay:**

My children are 31 and 28. So that's been very positive. I mean, my son, when I was diagnosed, was 26, my oldest son. And fathers and sons, we were having the occasional sort of spirited comparison of points of view.

**Carol Preston:**

How diplomatic.

**Jay:**

Really, all of that disappeared. Our differences became far less important in the wake of my diagnosis than our common ground.

And I'd say that's true across the spectrum of my family relationships. I happen to have a very good family experience. We've all been through lots together. But we've been fortunate that we all, I think, I worried a little bit when Elaine said 36 years and wanted to do it 20 years earlier. I thought maybe I should chat with my wife when she gets home.

**Elaine:**

It was just me.

**Jay:**

But I just have a good and highly supportive family situation. And yeah, my circle has become smaller in the sense that this has just made me look at what matters and disregard the things that don't. And there's so much that doesn't.

I work in a community that has about—I live on campus of a boarding school. So there are all kinds of times you can get dragged down by gossip and nonsense of all different kinds. And not that I participated much in it previously, but now, I don't participate in that sort of negativity at all. It's that sort of striving you do in your 30s and maybe 40s, too, in applying your ambitions and worrying about what other people are doing. And all of that I've just kind of set aside.

**Carol Preston:**

There is something very liberating, as we get older, especially for those of us who have gone through this diagnosis or many diagnoses of saying this the work that I'm going to do. These are the people with whom I choose to associate. And just push aside the detritus, if you will.

And, Derrick, you have two grown children I think about a decade older than Jay's. And I'm wondering about the influence in terms of the mind/body connection with your family as well.

**Derek:**

My children, my daughters are 40 and 43. And my son is 41. They have their own lives. And as I said, when I was diagnosed, my daughter flew here from Australia and took over the business. But I can't say enough what my family has done for me and my wife. And people come up to us, and they offer sympathy. Oh, you look well, and the things that they say to you. But they almost look through your partner. And what the partner goes through, and the stress they go through, is really, in many ways, unrecognized.

And so I can't talk enough about, my wife, particularly. I had to find something. I had to find some way to cope. And we talk about we don't know what's around the corner. We don't know what's there tomorrow. I call it the Sword of Damocles. And I keep looking up because I know it's coming down. I don't know how fast, but it's there. One day, it's going to hit me again. I'm sure. Maybe not, but you just don't know. And that's the horrible thing about what we go through. You don't know. Nobody can tell you. We're all individuals. So how do you cope? I cope through music. I've found music.

And when I get down, and I still get down, I still get depressed. If I can go out and play some music, I just go somewhere else. I'm not there anymore. And when I come back down to earth, when I step off that stage, wherever I am, that's my drug for the month.

**Carol Preston:**

It's a wonderful drug. And you have a website, don't you, where we can come and listen to the music?

**Derek:**

Yeah. The website is called H-A-E-M-O, Haemo Blues. It's spelled the English way, haemo, short for hemoglobin, obviously. But that came about because when I found music, I thought what am I going to do with this as well? So I decided to put back my creative fun for patients in the hospital just patient fun. And I got to know some incredible people who supported me all along the way. They're like family to me now, the guys in the band. We don't play very often anymore. Just out of interest, if I could do a quick bite; I'll be very quick, the Songs for the Unsung. And we're doing a concert in October to say thank you.

**Carol Preston:**

Wonderful.

**Derek:**

And that's how I manage to cope.

I will say other things, I wish I did, but I don't have any spirituality.

**Carol Preston:**

What I'm hearing is, from each of you, and then, Lisa, of course, I'm a big fan and a member of the website. And I know you do more than the website. But each of you has found, and I think we all do this as patients, you have found an element. You have found a signature activity or focus to make sure that you can get through those tough days, those down days. I totally empathize with the Damocles sword. I relapsed once. And when I finished my first round of treatment, rather than feeling joyous, and I had friends take me out to lunch that day, and I should have just been feeling incredibly joyous, I remember thinking, oh, no, there's no more treatment. How long will it be before the sword falls?

It was three-and-a-half years. It did fall. But since then, even though I know it still can be hanging up there, you know that it can fall, and that's the way it is. But I really am taking such great joy in hearing the elements of focus that you have all woven into your life. And, Lisa, you, in addition to the jewelry, have really you devote so much time to this website for women. So that's part of your focus, too, isn't it?

**Lisa:**

Yes, actually, helping other patients really helps me, and it helps the other patients also during my down time. I learned through all of my challenges over the last six years, I've pretty much, myself, I learned to leave everything in my doctor's office. I don't want to be bothered with if I don't have to deal with my cancer at any given moment, I'm very happy to just leave it and let it sit in my doctor's office, because I want to enjoy my time when I'm not actually dealing with my challenge.

So I'm really good at distractions. And I take care of my daughter's dogs. And I spend a lot of time with her. We go to the barn. She trains horses, and she trains dogs. And that's another favorite thing of mine to do is watching her training her horse and spending time with my grandkids. And I do quite a lot of research. And I'm an avid reader.

And I feel pretty comfortable, because I know where things are going. And I know that we have so many more choices today. And I know my doctors are really good at what they do. And they've showed me that. And I've gotten through a lot. So it's easy for me to just leave it there and do what I enjoy doing for me and taking care of myself and doing the things that I have control over. And that is my diet, my exercise, visiting my daughter, getting my infusions for my IBIG treatments, and just trying to enjoy my life as much as I can. Now, for me, I have a family history of this lymphoma.

So this wasn't a surprise for me. Although, I wasn't too happy about it. I had gone through AML with my mother, and that was quite an experience.

So when I was diagnosed, it was like now what? I wasn't really too surprised.

**Carol Preston:**

But we always hope it's not going to happen to us.

**Lisa:**

Yes, we do always hope it's not going to happen to us. But, usually, if something is going to happen to someone, it's going to be me. And that's kind of the way it's been. But, like I said, our doctors are so good at what they do that I just let them deal with it.

**Carol Preston:**

And I think that a lesson that all of us have learned, Elaine, you're in Boston, Lisa, you're in Seattle, Nova Scotia and Vancouver, is to find that specialist, to get that second and/or third opinion to make sure that the treatment options are right. We can't control—when I say we can't control the disease, we can't control that we got it, but we certainly can do some things to help ourselves keep it at bay and move it forward.

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